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PRIORITY EDUCATIONAL SERVICES FOR CHILDREN WITH DOWN SYNDROME IN IRAN

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ABSTRACT

Introduction: Down syndrome (trisomy 21) is the most common chromosomal abnormalities. And considering the fact that although there are common characteristics of Down Syndrome. But each person is unique, should these patients to the services required in the fields of medical, rehabilitation, educational, vocational, social, recreational, sporting and supportive (judicial-legal, financial) guided. The aim of this study was to evaluate the service was conducted from the perspective of their families. **Methods:** The study was a descriptive cross - sectional. Where 80 families registered with the Association of Down's syndrome (47 families with boys and girls educable 33 families residing in Tehran), the sampling method chosen. Patients aged 6 to 36 years and a two-stage tool was developed by a team of specialists, has been used. The data obtained were analyzed by the software SPSS19. **Results:** Study of the major problems in the eight groups showed that patients with high priority scores required services close 19.53 (SD = 2.33) is 20. Most families would necessitate the need for rehabilitation (%17) and %15 of vocational training was required. % 81.3 of children with Down syndrome, emotional acceptance, and a good solid %90 plus their families. %30 of patients in Amvrshkhsy independent, so that the difference between doing the job mothers was observed ($\chi^2 = 202.079$, $p < 0.05/0$). **Conclusion:** The results of this study showed that children with Down syndrome and their families through adoption is a good accompaniment. And this has effect on their privacy in personal affairs. Families in need of services will necessitate 8, and training in this area is important. Therefore it can be concluded that health promotion programs is used for children with Down syndrome.

Keywords: Down Syndrome, Education, Child

INTRODUCTION

Down syndrome which is a chromosomal disorder is most significant and known result of mental retardation in human communities (Mégarbané *et al.*, 2009).

In the most common type of the disease which is observed in 90 cases, there are 3 chromosomes instead of two number 21 chromosomes in the affected individual cells. The cause of this incident is a phenomenon known as nondisjunction of chromosomes (Ghosh *et al.*, 2010). Although the main cause of the disease is unknown, but its mechanism is the lack of separation in chromosomes the result of which is the birth an individual with 47 chromosomes (Cho *et al.*, 2013).

This type of Down syndrome (trisomy 21) is one of the most common genetic disorders in humans that includes a large part of about 35 to 37 percent of the mentally retardation (Rouin *et al.*, 2006). According to scientific reports, 80 to 95% of patients with trisomy 21, have an extra chromosome with a maternal origin (Ali, 2009).

Down syndrome occurs in about 1 in 650 to 1,000 live births (Kaplan *et al.*, 2010). The prevalence of this syndrome is one in 814 live births (Dastgiri *et al.*, 2010).

Researchers have conducted several studies to identify the various physical and mental aspects of this chromosomal syndrome, including studies of sensory, perceptual, motor, cognitive, emotional, physical and functional states in these patients compared to normal subjects (Super and Lamme, 2008).

According to these studies it has been indicated that in Down syndrome there are symptoms like, brachycephalic, weight loss of the brain, cerebellar hypoplasia, smaller hippocampus, narrow upper

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temporal gyrus, disproportionate size of the temporal lobe in comparison to the normal condition, the disproportionate of gray and white matter in the temporal and parietal lobes that these differences result in less muscle tone, sensory problems, motor coordination problems, impaired executive function, deficits in verbal comprehension and expression, problem in attention and memory (Fudge *et al.*, 2010).

In patients with cardiac disorder, about 4-10% of the patients had Down syndrome and about 40-60% patients with Down syndrome has congenital heart disease and cardiac disorder is one of the main causes of mortality in the first two years of life (Fudge *et al.*, 2010).

Patients with this syndrome have various disorders in different organs and although their life expectancy has increased in recent years, but the increase are still in the range of 40 to 60 years. Therefore, awareness of the problems of these patients and effective dealing with them is necessary (Behrman *et al.*, 2004).

The most important issue of this patient is the burden imposed on their families (Rozin and Nancy, 2003). In addition, maintenance and training, particularly with regard to behavioral problems and lower IQ will require additional activity and costs (William and Cohen, 2000).

Many problems in patients with Down syndrome is treatable, and life expectancy has increased in them. But Down syndrome cannot be fully treated and eradicate, but its symptoms can be relieved. Medical care and rehabilitation services, especially speech therapy and occupational therapy improve the quality of life of these people infinitely. Therefore the treatment should not be delayed or interrupted for any reason (William and Cohen, 2000). Previous studies have indicated that the role emotional acceptance of patients and their well-accompaniment with these patients is very important so that having a disable child significantly affects the psychological status of parents and causes stress in the family (Oskive *et al.*, 2007; Zombat and Yildiz, 2010; Totsika *et al.*, 2011), and meanwhile the highest mental stress is on mothers (Hastings, 2003). According to their personality structure, mothers feel themselves to be more responsible and sometimes feel guilty. Since they spend most of their time and energy to their children and as they have relations with neighbors, relatives and family more than fathers, they more exposed to explain about their child's state (Weiss, 2002; Baker *et al.*, 2005; Hastings *et al.*, 2005) and therefore these mothers have less physical and mental health Dorothy, Burdine *et al.*, 2005; Rihanna and Rosenbaum, 2005; Dale, Jahuda and Nat, 2007 and the prevalence of mental health problems, particularly depression is higher among them. (Singer, 2006) which could restrict their role in the management of child diseases, causing emotional and psychological problems in children and according to (Shio, 2007; Bartlett *et al.*, 2004; Rihanna and Rosenbaum 2005) affect the family's ability to cope with the disease of children (Ekas *et al.*, 2009; Zombat and Yildiz, 2010; Totsika *et al.*, 2011; Hastings, 2003; Weiss, 2002; Baker *et al.*, 2005; Hastings *et al.*, 2005; Duarte *et al.*, 2005; Riana and Rosenbam 2005; Dale *et al.*, 2007; Singer, 2006; Schieve *et al.*, 2007). The researches provide a lot of evidence regarding that the effects of having a child with special needs, is a combination beyond the care, education and the need for services. In his research, Malekpour 1999 states the most important needs of parents regarding their mentally retarded children as: the need for information, the need for support the family needs (Malakpour, 1998). Broder (2006) has considered the early intervention role in rising awareness of the parents and their consistency. Broinsma and Quil 2004 have mentioned the effect of education on the improvement of parents' emotional states and stress reduction. Dunset and Deil 1994 also state that involving parents in the services and supporting them will help decision making (Bruder, 2006).

The aim of this study was to determine the problems of people with Down syndrome in different fields of medicine, rehabilitation, education and vocational training, social and legal requirements; therefore, this study intended to investigate the educational methods that these families conduct on these children, through observation and questionnaires, and then prepare and present the training methods of individuals with Down syndrome due to their educational needs and the use of resources and research.

MATERIALS AND METHODS

Methodology

This is a cross-sectional study. The study population has been 80 families registered in the Down Syndrome Association in Iran (47 families have boys and 33 families have educable girls living in

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Tehran). The sample size was estimated to be 70 according to research conducted in this field on the basis of a formula to determine the sample, with a confidence level of 95% and test power of 80%, and due to the 10% loss, 80 patients were selected through nonprobability sampling. The age range of patients was 6 to 36 years and a two-stage tool with 8 axis was used which is prepared by a group of experts. The obtained data was analyzed using SPSS₁₉ software.

Sampling was done conveniently. In such a way that the employees who do not meet the inclusion criteria (willingness to participate in the study (the desire to participate in the study - the family of the patients, the educable adolescents and young adults with Down syndrome in Tehran who are in contact with the Association for Down syndrome), were excluded from the study. The information for this study was collected through a questionnaire designed for this study.

The questionnaire consists of two parts. The first part consisted of 13 questions about demographic data (age, sex, education, marital status, employment status, experience and number of children, affected child, father's date of birth, father's education, and father's occupation, mother's date of birth, mother's education, and mother's occupation). Part II includes required services including: Medical - rehabilitation - education training - professional educational - legal services, etc. (an 8-option question), the relationship between family members (father, mother, sister, brother) with the child with Down syndrome, Down syndrome child relationship you with other family members (father, mother, sister, brother) (two 4- and 5-option questions) and the independence level of children in private affairs like taking a bath – going to the bathroom - eating - clothing – putting on shoes - personal hygiene, etc. (a 7-option question) about the family load of patients with Down syndrome was family time. In each question 1 score was considered for each “yes” answer and zero was considered for every “no” answer. In the developing stage of the questionnaire of the required services, the families were asked to write their ideas regarding the 8 major problems of themselves and their children, according to the questionnaire, and give it a score up to 20 depending on its importance.

Using books and literature prepared by the researcher and colleague the questionnaire was prepared and through determining the validity of the questionnaires through face validity, content validity (quantitative and qualitative) was assisted by a panel of experts, in such a way that the prepared questionnaire was delivered to five health professionals, infectious diseases and their suggestions and comments were applied.

The reliability of the questionnaire was measured in a research conducted by Gholamnezhad (2009) which was estimated to be $r = 79\%$ through the correlation coefficient. The researcher used test-retest reliability; so that the questionnaire was delivered to a group composed of 10 subjects for two times in an interval of 7 days, then the results of the two tests were analyzed using Pearson correlation coefficient. The correlation coefficient between the two questionnaire tests was obtained to be $r = 76\%$ (Gholam and Nikpeyma, 2009).

All families participated in the study, and the data were collected immediately after the completion of the questionnaire. The questionnaire remains confidential. Before the data collection they were talked to and they were explained about the purpose of the study and the confidentiality of their responses, and verbal consent was obtained. They were assured that their responses would not affect the evaluation of their work.

The gathered data in the analysis stage was coded and was analyzed through SPSS 19 and applying and descriptive and inferential statistical methods with the help of Chi-tests and then the results were evaluated and reported.

The aim of this study was to assess the state of children with Down syndrome and its impact on families, which deals with the problems they are involved with, including training and educational methods different to them. This study aims to investigate the educational methods that the families of these children apply to them through an observational study and using a questionnaire, and identify their weaknesses and shortcomings and provide and present the educational package due to educational deficiencies and using of resources and researches conducted in the field of teaching methods to patients with Down syndrome (the research population of this study).

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RESULTS AND DISSCUSION

Results

The results indicated that the majority of the parents of children with Down syndrome, in (30%) of them father is at the age group of 51-60 and in (37.5%) of them the mother is in the age group of 41-50 years. In terms of education, parents of children with Down syndrome mostly have university educations and regarding the occupation, fathers are mostly retired and mothers are mostly housewives. In connection with the demographic characteristics of patients with Down syndrome, the results indicated that most of these patients are between the ages of 11 to 20 years.

The required services, according to the families, were the result of 80 cases that been scored with the minimum of 15 and maximum of 20. Therefore, according to the experts' point of views 8 different axes were designed and the score of each axis has been extracted from average score of the sub-group options and are provided in table 1.

Table 1: The score list of the 8 axes for the required services

The required services	Average score	Standard deviation	Frequency (%)
Medical	19.08	2.06	7 (8.75)
Rehabilitation	19.83	2.58	13 (16.3)
Education	19.53	2.23	11 (13.75)
Professional	19.76	2.52	12 (15)
Social	19.83	2.53	7 (8.75)
Recreation	19.43	2.19	9 (11.25)
Sports	19.72	2.48	10 (12.5)
Support (legal, financial)	19.12	2.08	11 (13.75)

As indicated in Table 1, more than 17 percent of patients need rehabilitation and 15 percent need vocational training. 11 percent need a combination of medical - educational - professional - legal - recreational – sports services.

Table 2: Distribution of the study sample based on the relationship between family members with the patients with syndrome (Down)

Type of relationship	Frequency
The relationship between family members with the patients with syndrome (Down)	
Well - accompaniment	72
Accepting- tolerable	6
Ignorant	1
Objecting	1
the relationship between the patients with syndrome (Down) and the family members	
Emotional	65
Normal	15
Total	80

As indicated in Table 2, the relationship of about 90 percent of family members is good with the patients with Down syndrome. This means that in most activities they follow him and the patients with Down syndrome are accepted as an independent member in the family. Also the relationship between the patients with Down syndrome with the family members is emotional and along with psychological dependence. There is also a significant relationship between the relationship between family members and child and the child's relationship with family members.

One of the result of this study indicated that, approximately 30 percent of the patients are independent in activities such as taking a bath, going to the bathroom, eating, clothing, putting on shoes and personal

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hygiene are independent. Note that patients with Down syndrome are independent in most of their personal affairs, and therefore there is no significant relationship between doing the personal affairs of these individuals and their parents' education and their father's occupation.

Table 3: The two-variable Chi-square of performing personal affairs with regard to the parents' occupation and level of education

Two-variable Chi-square	Frequency	Df	P
Personal affairs – father's education	60.101 (a)	80	0.953
Personal affairs – mother's education	87.552 (a)	80	0.264
Personal affairs – father's occupation	90.920 (a)	76	0.117
Personal affairs – mother's occupation	202.795 (a)	140	0.000
The relationship between family members and patients with Down syndrome – rehabilitation services	106.32 (a)	3	0.000
Personal affairs - Rehabilitation Services	156.77 (a)	20	0.000
The relationship between family members and patients with Down syndrome – father's occupation	85.875 (a)	4	0.000
The relationship between family members and patients with Down syndrome – father's education	63.875 (a)	4	0.0004
The relationship between family members and patients with Down syndrome – mother's occupation	181.100 (a)	3	0.000
The relationship between family members and patients with Down syndrome – mother's education	85.875 (a)	4	0.000
The relationship between family members and patients with Down syndrome and vice versa.	0.333 (a)	1	0.564

In analyzing the relationship between performing personal affairs with regard to the parents' occupation and their level of education, the results of the two-variable Chi-square test indicate that: there is no relationship between performing the personal affairs of individuals (children) with the education level of parents (father and mother) and father's occupation ($P > 0.05$) but there is a significant relationship between performing the personal affairs (child) with the mother's occupation ($P < 0.05$). There is a relationship between family members and patients with Down syndrome and rehabilitation services, personal affairs and rehabilitation services, the relationship between family members and patients with Down syndrome and father's occupation - Education – mother's occupation and mother's education.

Discussion

Findings of this study are consistent about the age, education and father's occupation and are in line with the researches of Hoter (1989), Stene (1981) and Roth and his colleagues (1983) (Heuther, 1983; Stene and Stene, 1981; Roth and Bigel, 1983).

The findings about the services for people with Down syndrome are consistent with researches that Merik (2004), Lund (1988), die (1998), Felie and Jones (2007) and Filder and colleagues (2006) have done about the problems that people with Down syndrome have, the results of this research indicate that people with Down syndrome have more motor-behavioral problems and before anything else they need rehabilitation support (Merrick, 2004; Lund, 1988; Feeley and Jones, 2007; Dianne, 1998; Fidler *et al.*, 2006). "In addition, researches in accordance with the present study have shown that participating in daily sport - recreational competition (playing at home and at school), and other Professional training can also improve to a great extent social skills about the services that are required for these people (such as self-care) (Rahbanfard, 1988; Klein *et al.*, 1993) and also participation of the patients with Down syndrome in sport activities in view of (Sanier, 2011), have numerous physiological and psychological benefits (Sawyer *et al.*, 2011).

"Researches and experiences from the study on mental abilities and actions of these children in view of Rahbanfard 1377, show that a high percentage of them have successfully finished education, such as

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reading and writing and arithmetic that the results show the importance of the required training services in this study (Rahbanfard, 1988).

The findings about how individuals with Down syndrome communicate with family members are in line with the results of Atkinson *et al.*, (1994) and Williams (2000) (Atkinson *et al.*, 1994), (Cohen, 2000). They conducted a study that found that people with Down syndrome have compatibility with their family members and emotionally are dependent on family members. Also, according to (Borella E *et al.*, 2013) their families have an accepted good relationship (Borella *et al.*, 2013).

"The results are in line with the studies of Summers 2008, Pourseyed 2010, Dorfard 2006, Behrad 2005 that the results showed that increasing life skills and independently doing personal affairs in patients, leading to social adaptation, improving social relationships and reducing conflicts (high risk behaviors). And are inconsistent with the researches of Soleimani and colleagues in 2011, which reached the conclusion that social skills training had no effect on daily living skills. Studies have shown that patients with this syndrome should participate in daily domestic work, because it is important in to increase their confidence and independence.

In line with this study interaction of parents with children can have a major impact on social and family perception (Wong, 2003) and according to (Asvart and Dyson, 2005), the development of social, emotional skills of children with learning disabilities (Wong, 2003; Swart *et al.*, 2009).

Conclusion

Overall, by evaluating the study results, we find that people with Down syndrome have certain differences in terms of cognitive, motor, social, and other needed services that the type of activities and the daily schedule must be compatible with it.

Most studies on the disease have taken in the field of intelligence, social issues and cognitive domains of these people. But the main topic is providing any health plan that is directly necessary on these patients. According to the results and findings of the study it seems:

1. Informing the families of persons with Down syndrome about demographic differences and physical, social, mental, and emotional condition... and necessary by the media and authorities about the provision of the required brochures and books, making interaction with these families and communities, and publishing the results of researches in this field.
2. People with Down syndrome, despite their limitations have a very good acceptance in the studied families and the families willing to provide any cost and are supportive. But the public social security system and health and welfare services should especially do something for the patients and families in the fields of insurance, legal matters and other supportive issues.
3. Lack of effective social communication - the impossibility of marriage and lack of predicted jobs for this group are the most important concerns of the families. Therefore, training in socialization of these patients is necessary.
4. Appropriate programs to inform, create interaction, provide the educational needs of patients and their families provide books and educational materials, and predict and provide jobs for these people are essential.
 1. One of the services needed by people with Down syndrome is rehabilitation services, in this context, mechanisms must be provided by relevant organizations.
 2. Considering the rights of persons with Down syndrome in the community and supporting and protecting the individuals by the Ministry of Labor, Cooperatives and Social Welfare.

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